Cancer Patient Navigation

Evaluation Findings
Summary Report

March 2004

Cancer Patient Navigation Evaluation

Summary Report

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461-7005Q

Prepared for:

Cancer Care Nova Scotia

March 2004

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Executive Summary

104-05532/

Results of the **Cancer Patient Navigation Evaluation** confirm that the program has significantly benefited cancer patients and their families in dealing with the emotional turmoil, informational needs and logistical challenges associated with having cancer. It has resulted in more efficient use of clinical time for physicians and more appropriate use of community health professionals. The program has contributed to overall improvements in the cancer care system itself by addressing problems related to integration, coordination and continuity of care. There is strong evidence to support the implementation of Patient Navigation in the remaining health districts.

This evaluation integrated information from a variety of different sources. It included 16 focus groups, 57 one-on-one interviews, 162 patient surveys, and a review of 808 records in the patient navigation database. Multiple stakeholder groups participated in the evaluation, including patients and families, community partners, such as, home care, Canadian Cancer Society staff/volunteers, physicians, other health professionals in the districts and at the cancer centers, Patient Navigators, senior leaders in the "early adopter" districts, and key *Cancer Care Nova Scotia (CCNS)* staff.

The evaluation confirmed that Patient Navigators have significant knowledge and awareness of the provincial cancer system and community supports and resources. Using this knowledge has played a key role in improving overall quality and consistency of cancer care in the district which has resulted in: more awareness and utilization of community supports, identification of community service gaps, increased collaboration among health care members, improved coordination between community services and tertiary centres, more consistency in cancer care, earlier referrals to oncologists and providing a new source of oncology expertise to the community. In addition to the introduction of the patient navigation program, many felt that the establishment of district cancer committees and *CCNS*' direct involvement within both of these programs has served to give cancer care a high priority at the district level.

The program is meeting the expectations of health professionals, community partners, and senior leaders in the district. Patient Navigators are described as providing consistency in care by having one person from their area that is a constant for patients, health professionals and community partners throughout the cancer journey. This fulfils a supportive role for the patient, and helps provide better coordination and consistency of care in the district. Most district health professionals cannot imagine cancer care in the districts without a Patient Navigator and there is widespread support from senior leaders, health professionals and the community for the program's continuation.

The consistently recognized benefits of navigation for patients and families include: providing emotional support, preparing them for their cancer journey, referrals to appropriate health professionals, increasing their knowledge about cancer, helping with coordinating appointments, referral to community supports, assisting with the logistics of getting to cancer centers and finding sources of funding for medications and supplies. The results show that the Patient Navigators have become, for many patients and their families, a central contact and this assistance is highly valued. A comparison between patients' expectations and satisfaction with the services provided indicates that the Navigators are closely matching expectations in assisting patients and families with multiple issues.

Health professionals value the patient navigation program and credit the program with: better patient preparedness, providing more support for patients, improved collaboration among health professionals, more efficient clinical involvement with patients, and identification of service gaps. Navigators have become one of the primary sources of assistance for patients, along with family doctors, oncologists, and staff at the cancer centres. It was identified that the Patient Navigator does not replace other sources of support, but rather complements and reinforces the support, information and education provided especially by physicians. Patient Navigators were acknowledged as a source of information for health professionals, and patients and families. Navigators are identified as the linkage among different components of the health and cancer system and as educating the cancer team to be more aware of services and actions other team members are providing.

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This is reducing duplication of services resulting in efficient and cost effective care. The increased collaboration that has occurred was attributed to the Navigator role and physicians noted that further strengthening these linkages would serve to improve efficiencies in patient care.

Various factors have contributed to the program's success. These include; commitment of district senior leaders, health professionals and all those involved in cancer care, extensive communications and having the right professionals in the Navigator positions. Patient Navigators need to have an understanding of cancer, extensive people skills, and be self-directed. The Navigators must also have or be able to develop an in-depth knowledge of the multitude resources available to assist cancer patients. Additionally, support from *Cancer Care Nova Scotia* was considered instrumental by district staff to the success of the program. *CCNS's* role includes not only financial support, but also the overall vision and direction for the program, providing and directing orientation and continuing education opportunities for Navigators and coordinating the network among them.

There are a number of challenges to be addressed by the program including; encouraging a greater number of referrals; increasing the timeliness of the referrals received; and more continuous communication about navigation with health professionals. For the districts with large geographical areas, strategies to ensure equal access to the navigator should be considered. As the program moves forward, careful monitoring of the roles and priorities of Patient Navigators, along with their workloads is recommended.

Navigation has been successful at integrating institutional and community based care and effective at balancing health professional and patient perspectives. Navigators have been able to improve patients' ability to cope with a critical illness which research has concluded is ultimately more cost effective care. Patient navigation has met its goals and the findings provide strong evidence to support cancer patient navigation implementation in the remaining health districts. All key processes and structures are in place to ensure program success and *CCNS* is prepared to take the program forward.

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Summary Findings

The Partnership

In February 2002, *Cancer Care Nova Scotia (CCNS)*, in partnership with three District Health Authorities, implemented Cancer Patient Navigation; a client centered, outcome-focused care management approach. The three "early adopter" health authorities were: Southwest Health, Pictou County Health and Guysborough Antigonish Strait Health (GASHA).

Cancer Patient Navigator Role

Cancer Patient Navigators work with cancer patients, throughout a District Health Authority, to address a wide range of patients' physical, psychological, social, emotional, informational and practical needs. They work in partnership with a broad network of community health professionals and resources. Navigators are intended to enhance the community's capacity to support both people with cancer and their caregivers by providing a single focus point for coordination, transition and integration of services. Navigators support health professionals, especially the family physician, in the community, by providing cancer-related expertise and knowledge about the cancer system, its resources and processes.

The initial goals of the program were to:

- Ensure cancer patients and their families have the information, knowledge and support they need as they journey through the cancer system;
- Assist family physicians, surgeons, community-based specialists, oncologists and other health professionals to provide optimal cancer care; and
- Enhance district health authorities capacity to care for and support people with cancer.

The Evaluation Process

In June 2003, Capital District Health Authority Research Ethics Board approved a peer reviewed evaluation protocol for scientific validity and ethical acceptability. *CCNS* commissioned Corporate Research Associates (CRA) to conduct the evaluation. Multiple stakeholder groups participated in the evaluation, including patients and families, community partners, such as, Home Care Nova Scotia, the Canadian Cancer Society staff/volunteers, physicians, other health professionals in the districts and at the cancer centers, Patient Navigators, senior leaders in the "early adopter" districts, and key *CCNS* staff. The evaluation incorporated both qualitative and quantitative research methods. Data for the evaluation was collected through 16 focus groups, 57 one-on-one interviews, 162 patient surveys, and a review of 808 records in the patient navigation database. A full description of the methodology, analyses of data and the findings are presented in a detailed report. The evaluation was a retrospective study conducted to:

- Clarify the role of a Cancer Patient Navigator and the best approaches to improve coordination and continuity of care;
- Determine the effectiveness of the processes used in cancer patient navigation;
- Measure the impact cancer patient navigation has had on patients/families and health professionals particularly the family physician and medical oncologist;
- Measure the impact cancer patient navigation has had on the development, organization, and utilization of cancer services within the "early adopter" sites; and
- Describe the issues relevant to implementation that should be considered before cancer patient navigation is implemented in remaining health districts.

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Key Findings

Key Finding 1 Cancer Patient Navigation has improved the quality and consistency of cancer care in the districts.

Community partners reported that having **one person from their area** that is a constant for patients, health professionals and community partners has improved **consistency** and quality of cancer care. This fulfils a supportive role for the patient, and helps to provide better **coordination of care for health professionals**. Patient Navigators serve as a linkage or interface between patients and families and the cancer care system. Community partners indicated that having a Navigator results in appropriate and timelier referrals to services for patients. They also indicated the Navigator is often the linkage for patients with provincial services.

A number of district service providers reported that their level of involvement with patients has increased especially for nurses working in continuing and palliative care settings. They reported being more aware of cancer patients' needs and thereby providing more services to a greater number of patients.

> *"I have seen an improvement in care and communication with cancer patients and families from several points of view: 1) They have access to someone who will provide them with information and support as they go through their illness; 2) The Navigator has an excellent knowledge of available resources and has been providing good follow-up and referrals to appropriate people." Community Partner*

Most community partners, senior leaders and health professionals, noted Navigation has improved development and utilization of cancer care in the districts. All participants who had the opportunity to work with Patient Navigators indicated they could not imagine the district without such a position. Improvements to the district cancer system as the result of navigation include: better awareness and utilization of community supports, greater consistency and coordination of care, increased and earlier referrals to oncology, increased contact between district and cancer centre, and more referrals to home care and palliative care.

> *"Because she is there we are delivering better cancer care, we are providing more services to patients and there is an increased use of services." Senior Leader*

Findings from Patient Navigators, senior leaders, and *CCNS* staff indicate that Navigators are identifying needed community cancer resources and services, such as patient education materials, counseling, home care and palliative care. Patient Navigators bring their knowledge and experiences to various committees and clinical rounds, extending the knowledge about quality cancer care to the community team. Findings also indicate that the Patient Navigator has become the cancer professional with the most centralized knowledge of available community resources and services. This has facilitated appropriate referrals to other health professionals and services in the community. The database confirmed 92 new referrals made to home care, 62 referrals to palliative care, 134 referrals to CCS, and 124 referrals to support groups during the first 18 months.

Senior leaders and a number of health professionals indicated, that since the establishment of patient navigation, they perceive a greater awareness and collaboration among health professionals at the district level. Health professionals are referring patients to the right resources.

> *"I find I am more involved than ever since the Patient Navigator because we are more aware now of all the new cancer diagnoses. The Patient Navigator has helped a lot...It has opened our eyes to the fact that these people have needs that are not being met, so we have looked at that, I have brought that up to my supervisor and the Patient Navigator and I meet with them and now we are offering supportive visits through home care Nova Scotia. The way that we do it is we give them teaching visits regarding their new cancer diagnosis. Before they weren't offered that." Nurse*

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Key Finding 2 **Cancer Patient Navigation is viewed as an integral component of district cancer services and there is widespread support for the program among health professionals, patients and families, and administrators.**

Participants overwhelmingly supported the continuation of the patient navigation program. In fact, when asked to rate how important it is to continue with a patient navigation program on a scale of 1 to 10 where 1 was not at all important and 10 was very important, community partners almost exclusively gave ratings of 10 (although some indicated 10 plus), while a few individuals indicated a rating of 9. The program is now viewed as an integral component of cancer services in the "early adopter" districts bringing considerable benefits to cancer patients, their families and health professionals working with cancer patients. Patient navigation is viewed by the senior leaders and health professionals in the districts not only as essential, but critical.

"It (Patient Navigation) is so fundamental to the goals of quality, evidence-based cancer services, client satisfaction and improved primary health care in the community." Senior Leader

"A Patient Navigator is extremely essential to this area. Patients need this one on one support to go through their cancer journey. She relieves a lot of stress that most patients don't need. The Patient Navigator pilot project is the best thing that has happened in this area for cancer patients." Community Partner

Key Finding 3 **Cancer Patient Navigation is fostering collaboration and communication among health professionals and reducing duplication of services, which is attributed with more efficient and cost effective care.**

Forty interviews conducted with a wide range of health professionals working in the districts and at the cancer centers in Halifax and Sydney, found that the Navigators have met the majority of their expectations and in many ways have exceeded them. Health professionals expect Patient Navigators to provide assistance to cancer patients and their families as they journey through the cancer system, as well as foster communication and collaboration among health professionals. Health professionals indicated that the impacts of Patient Navigation include: better patient preparedness, more support for patients, improved collaboration among health professionals, and more efficient clinical involvement with patients.

Patient Navigators were acknowledged as a **source of information for health professionals**, as well as for patients and families. According to the database, health professionals and community groups looking for oncology information or education made up 24 percent of the 208 non-patient requests for assistance from the Navigators. A number of health professionals talked about Patient Navigators **linking together the different components of the health and cancer system.** Most felt that the cancer team was more aware of the services and actions other team members are providing. This helps to ensure that all members of the patient treatment team are aware of the patient's status and treatments each member is providing. This can help avoid duplication of services resulting in efficient and cost effective care. This increased knowledge was attributed to the Navigator role and the physicians interviewed noted that further strengthening these linkages would serve to improve efficiencies in patient care.

"Basically I see them as a liaison between myself, the family doctor and other health professionals ensuring that the patient has a smooth ride through the cancer system and when necessary arranging transitions to other services such as palliative care." Oncologist

Another positive outcome of the patient navigation program is the increased **collaboration and communication** that has taken place between health professionals, cancer patients and their families. A number of participants referred to the Navigator as the link among health professionals, especially the family physician and the staff at the cancer centres. Each Navigator serves as part of a cancer care team in their respective district and attends clinical rounds as part of that team. Nursing staff and other professionals

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including home care staff, dietitians, physiotherapists, and occupational therapists are essential contacts for the Patient Navigators to gain information and to refer patients to when required. In turn, these health professionals are sources of referrals for Navigators. Health professionals expressed the view that when a patient's treatment team is aware of the patient's status and the services or treatments each team member is providing, there is reduced duplication of services and more optimal care. As the program continues, collaboration and communication can be further developed.

> *"There is a lot more talk among health care professionals, between doctors and the staff with the Patient Navigator, there is more communication that way." Nurse*

Navigators are viewed by many as the centralized source of cancer information and education that has resulted in better use of clinical time for physicians and reduced anxiety and distress for patients/families. Family physicians and specialists reported that patient navigation has allowed family physicians and oncologists to focus on the medical issues, knowing that someone else is looking after the logistical issues.

> "Since *it started there is more coordination between surgeons, patients, family physicians, oncologists the whole team. There is more information sharing and families are more involved." Nurse*

Key Finding 4 **Cancer Patient Navigation has become an important source of support for patients and families in dealing with the emotional turmoil, informational needs and logistical challenges associated with cancer.**

Ten focus groups were held with patients/families in the "early adopter" districts to: discuss issues and challenges faced by cancer patients, identify their key supports, and share their knowledge and experiences with patient navigation. Two focus groups were also held in a comparison district, where patient navigation is not available, to identify patient and family issues and sources of supports. All patient/family focus groups identified the same issues and similar sources of supports. Patients in the comparison group felt their cancer journey might have been better if they had access to a central contact. These issues were confirmed by 162 patient surveys and findings from four focus groups held with community partners. The top four issues and concerns identified were (a) emotional impact /fear and stress, (b) dealing with physical symptoms/ complications, (c) getting to cancer centers in Halifax and Sydney, and (d) coping with financial impacts.

Patient Navigators were identified as significantly benefiting patients and families by providing emotional support, preparing them for their cancer journey, increasing the knowledge about their disease, helping with coordination of appointments, referring to community supports, assisting with the logistics of getting to cancer centers and finding sources of funding for medications and supplies. In the district without navigation, the comparison group identified the need for a central contact person as important. The database recorded 873 issues with a 94 percent successful resolution rate. The most common issues not resolved were financial assistance (25 percent) and emotional support (18 percent). No other specific issue comprised more than six percent. Patients and health professionals reported that those who were in contact with the Navigators were often better informed and less stressed. Database results indicate that 41 percent of actions taken by Patient Navigators in assisting patients involved the provision of information.

> *"If we had had a Navigator, it would have taken some of the pressure off because here you are trying to get information and you don't know what avenues you have open to you, you don't know where to go and you don't know what's available." Patient, Comparison Site*

> *"I went through it (cancer diagnosis) without the Navigator and with a Navigator and definitely with the Navigator it is easier to get through. The first time there was no support, no Navigator or anything, fear takes hold of you and you can't get a lot of your questions answered and it is a lot more stressful, not only on the patient, but on the family and everyone." Patient*

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Patients and health professionals reported that patients who were in contact with Navigators were often better informed, knowledgeable and supported. The patient survey and patient and family focus group discussions indicate that for many, the Patient Navigator has become one of the primary sources of assistance, along with family doctors, oncologists, and staff at the cancer treatment centres. It was identified that the Patient Navigator does not replace these other sources of support, but rather complements and reinforces the support, information and education provided especially by physicians.

"She's such an advocate for people, such a vital part of care of the patients." Nurse

"I think patients who had come to see me having already worked with the Navigator were much better prepared…because a lot of the emotional, valid concerns had been aired to some degree. They were much more ready to listen, hear, and accept the treatment plan because they had done that work already and quite frankly, they can do that work with an oncologist, that is not the problem. The problem is a cost effective one." Oncologist

Key Finding 5 **The referral process is open ended and flexible and is progressively moving forward as an automatic contact for patients with cancer.**

The program developed a written referral process with options remaining open for verbal referrals. Referral sources included patients themselves, family members and health professionals. Referrals came from different sources, which indicates program awareness is spreading across key groups. As indicated by the database reviews 63 percent of referrals came from health professionals, including family physicians, 20 percent were self-referrals while family members referred 13 percent. While not all cancer patients will need a Navigator or want to see a Navigator, it is an objective of the Navigation program to have all cancer patients aware of the service. Several health professionals report that they are progressively looking toward the Patient Navigator as the automatic contact for cancer-related issues.

Navigators reported satisfaction with the referral process, indicating that as long as they get the referrals it does not matter if it is written or verbal. The ability for patients or their families to self refer is an important aspect of the referral process. In the period reviewed one-third of all referrals were made by patients or their families

Key Finding 6 **Communication initiatives about the Navigator role must be continuous and hard-hitting to ensure all are aware about cancer patient navigation.**

There were extensive communication efforts undertaken to inform the public and health professionals about navigation and its services including letters to (a) all physicians, (b) community presentations, (c) one-to-one contacts, (d) an official launch in each district, and (e) development of branding materials including a logo for patient brochures and posters.

Health professionals, particularly physicians, indicated that more continuous information about the role of Patient Navigators is needed. Physicians interviewed indicated they recalled seeing information early in the program. However, most family physicians have small numbers of newly diagnosed patients per year and do not automatically think of patient navigation.

"The nature of the role (patient navigation) *is such that it does require continuous advertising and you have to recognize that the average family doctor only has one to three cancer patients in their practice at any given time, so they may hear about or use the Patient Navigator service in February, but then not have any occasion to think about it for a year and so when out of sight out of mind. You can't do a one off advertising education process, it has to be continuous." Specialist*

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"Substantial progress has been made in building program awareness. While the initial efforts were indeed intensive, this process needs to be ongoing and hard hitting to ensure it remains top of mind to everyone." Family Physician

A key challenge is to increase program awareness so all cancer patients can experience this support. Continuous communications will be required to health professionals in particular to ensure that all cancer patients and their families are aware of Patient Navigation and are accessing the program.

Key Finding 7 **Comprehensive orientation and ongoing educational opportunities are necessary for the success of the program.**

The Navigator's orientation plan is considered to be a key element in the ability of Navigators to better assist and support patients. Navigators reported it provided them with a better understanding of the process patients go through during their cancer experience and thus they are better able to provide necessary assistance to patients. The comprehensive orientation and ongoing education program established for the Navigators provided them with the opportunity to increase their oncology expertise and knowledge of the cancer system and process needed for coordination. It was an important way to be kept up to date on treatment protocols, care paths and establish credibility with the cancer team. The navigators presence at the cancer centres facilitated positive relationships with oncology staff and established buy in for the program.

Key Finding 8 **A network of Cancer Patient Navigators, coordinated by *CCNS*, is collectively a strong asset to the cancer system.**

Consensus among district personnel was that patient navigation was effective in each district. They indicated that patient navigation has been one of the most effectively implemented programs. Strong commitment from the district and appropriate support and guidance from *CCNS* is integral to its success.

"It is one of the most successful programs that I have ever been involved in…we thought it was going to be good, but it is better than our anticipated goals and objectives. Any other program that we have tried to do, there has been a catch, and there is a gap, or we haven't been able to recruit the right people. In this case, none of that happened." Senior Leader

District personnel considered the connection and support from *CCNS* as an essential component. They unanimously desired a strong involvement on the part of *CCNS*. The role of *CCNS* ensures that standards of practice are established and followed in each district and that accountability within each district continues. *CCNS* coordination and management ensures quality of care, standards of practice, and access to provincial expertise and resources to the districts. A network of Patient Navigators, coordinated by *CCNS*, is collectively a stronger asset to the cancer system. *CCNS* can assist the Navigators with education and problem solving. Navigators rely on this support network in performing their job. Education of Patient Navigators was also considered a part of *CCNS*' role and one that the Navigators personally thought was particularly valuable. The guidance and standards provided by *CCNS* and linkages to other districts was felt to help keep the program consistent throughout the province. Having the support of *CCNS* staff, the other Navigators, and district staff is an important source of support to Navigators. As a provincial body, *CCNS* should synthesize information from each district in order to provide evidence of issues in the cancer care system that need to be addressed by government.

Conclusions

The following conclusions have been made relevant to each of the five key evaluation questions. The conclusions are supported by key findings.

Conclusion 1

The current role is matching expectations of patients, families, physicians and health professionals and there is a high level of satisfaction with the role.

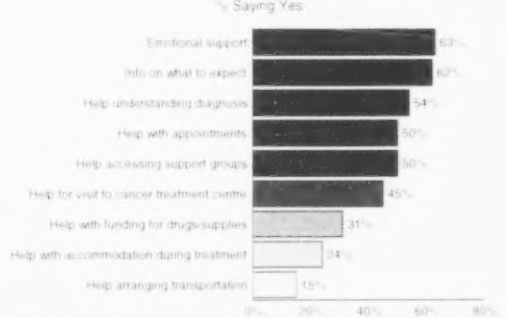
Expectations for Patients and Families

In the view of patients, families, physicians, health professionals, district leaders, community partners and the Navigators, the top priority for the patient navigation role is providing education, assistance and support to patients and families. Patients/families expect Navigators to; provide emotional support, increase the understanding about their disease, inform them on what to expect, coordinate and improve access to treatment, help with the logistics of getting to appointments and finding accommodations, and assist with dealing with financial impacts such as the costs of drugs and loss of income. The patient and family focus group discussions, patient survey, and database review, consistently identify the Patient Navigator as providing support in meeting these needs. Many patients report that the Navigator's support resulted in decreased anxiety, stress and fear.

> *"While I was waiting to find out whether I had to have chemo, the Navigator contacted me.... Gave me information as to what will happen, came to my home. It was very satisfactory. The literature was up to date, very informative and basic to what I needed...My contact with her was reassuring I knew that there was someone to reach out to, someone to give me information if I needed it or wanted it."*
> *Patient*

Figure 1 demonstrates the variety of assistance patients received from the Patient Navigator, as outlined by the patient survey. The survey results, along with findings from the focus groups, indicate that actual assistance received is meeting expectations.

Figure 1. Assistance Received From the Cancer Patient Navigator



Source: Patient Survey

In the survey, patients were asked to evaluate the importance of various aspects of assistance from Patient Navigators. This is presented in figures 2 and 3 below. It is clear that patients expect the Patient Navigator's role to be multi-dimensional. The high level of satisfaction further supports that the current role is matching expectations of patients. However, dealing with financial issues and logistical arrangements are areas where assistance is not rated as strong. These are areas where Patient Navigators have little control.

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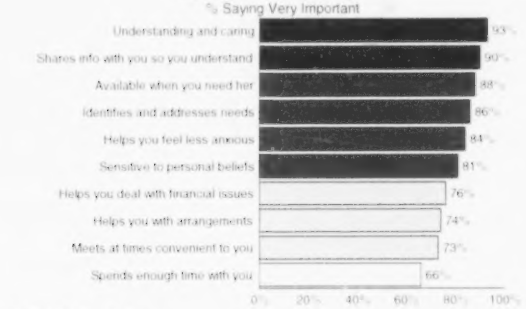
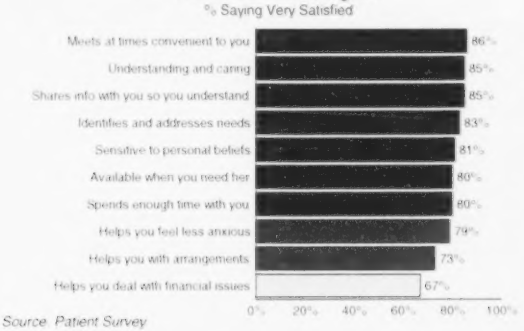
Figure 2. Important Aspects of the Cancer Patient Navigator



Source: Patient Survey

Figure 3. Satisfaction With Aspects of the Cancer Patient Navigator



Source: Patient Survey

Expectation of Health Professionals

The Cancer Patient Navigator role also encompasses assistance to health professionals. Based on the evaluation findings, health professionals' expectations for the Navigator position have a high correlation with the role. The role is credited with; better preparing patients for their visits to cancer centres, helping patients with logistical issues, allowing physicians to make more efficient use of time, working with cancer centres to coordinate patients' appointments and tests, and assisting with coordinating follow-up appointments locally. Because the role is a central contact person, health professionals have an expectation that the role could foster collaboration and communication among health professionals. Health professionals report that they are progressively looking toward the Patient Navigator as the automatic contact for cancer-related issues.

Health professionals frequently reported that patients who have received the services of the Patient Navigator were more prepared for their treatment visits. They reported that patients appear to be more aware of what to expect and what questions they should be asking. This required knowledge was seen as equipping patients with the skills and confidence they require navigating the cancer care system. Participants interviewed felt having this awareness prior to medical appointments and procedures helped to relieve some of the stress and anxiety patients frequently experience. Participants reported that navigated patients who wanted to take an active role in the selection of their treatment process appeared to be more knowledgeable. Simply knowing they have a specific person to turn to if any issues arise or if they have questions provided patients with an important sense of being supported.

> *"Patients and families feel they are well supported in terms of accessing the system from initial diagnosis right through." Nurse*

> *"I think patients are definitely more aware of what to expect, what they should be looking for, what they should be asking for, time frames for various things that should happen. I think the patients overall are much better informed." Community Health Professional*

Navigators felt their roles matched the intended functions of the position, however, a number of spin-off expectations had evolved. Navigators are frequently requested to be a member of any cancer related committee or initiative, both within the district and provincially. As the cancer care system in the districts gain momentum this could mean additional demands on Navigators' time for activities other than direct patient care. The program needs to be a balance between committee work and patient care, given that patient care is considered the most important component of the role.

The evaluation has concluded that the Navigator role is viewed as integral to the district cancer team. The role is seen as complementary and not a duplication. Key challenges for the role are heavy workload, burnout and

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covering extensive geographic areas. The database information suggests that proximity to the Patient Navigators' offices is linked to the likelihood of receiving referrals. Innovations that allow the Navigator to partner with community resources in more remote areas need to be formalized.

Conclusion 2

Appropriate processes have been established in the cancer patient navigation program.

The key processes involved in patient navigation are: communications, referrals, orientation/education, project management, data collection, and reporting. All of these processes were developed during the early stages of the program, in collaboration with *CCNS*, the districts and the Patient Navigators.

Communications

A broad program communication plan is fundamental to establish broad awareness, uptake, acceptance and credibility. Interviews with Patient Navigators, senior leaders, and *CCNS* staff confirm that communication was a key priority. There were extensive communication efforts undertaken to inform the public and health professionals about navigation and its services including letters to (a) all physicians, (b) community presentations, (c) one-to-one contacts, (d) an official launch in each district, and (e) development of branding materials including a logo for patient brochures and posters. Both community partners and health professionals report they felt well informed of the program, having learned of it through various and sometimes multiple avenues.

> *"The information is very well presented, it is very well written, it is very easy to understand for families and patients and it kind of gives them, especially when they are in crisis, it gives them something that is written that shows them that they are not alone nor will they be through this whole process." Nurse*

Referral Process

The program developed a written referral process with options remaining open for verbal referrals. Referral sources included the patients themselves or their families, health professionals, and community partners. Family physician referral was encouraged to enable the navigators to better support the family physician role. Patient Navigators indicated that most referrals are verbal. Attendance at various clinical rounds and chemotherapy clinics help Navigators identify potential patients. In some cases referrals sources are clinic nurses who notify navigators at the request from surgeons for automatic referral of all cancer patients. Eighty-four percent of the 598 patients referred were newly diagnosed; fifteen percent had a recurring cancer, one percent was for other reasons. The Navigators have reached patients with various cancer types, however, patients with certain cancers are accessing the Navigators more often. Patients with breast cancer accounted for 28 percent of referrals, cancer of the digestive system 22 percent, and respiratory cancers 12 percent. Patients with genitourinary cancer appear least likely to be referred to the patient navigation program.

The average number of days between diagnosis and referral was 49. This remained relatively unchanged over the 18 months. Efforts to stabilize the consistency and timeliness of referrals are warranted. Patients reported in the focus groups they could have benefited even more from the service had they been in contact with the Patient Navigator at the time of diagnosis.

Orientation and Education

Patient Navigators and senior leaders view the orientation and educational opportunities for the Navigators as both comprehensive and important. The orientation included an introduction to the cancer centres, a two-day

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oncology workshop at the QEII, and an overview of CCNS directions in cancer care. Ongoing education includes an eight-month continuing education program in oncology through the University of Alberta, participation in conferences, and ongoing sharing of current material, primarily through CCNS.

Program Management

In terms of program management and accountability, each of the districts established different reporting structures. It was noted the Patient Navigators are generally self-directed and independent regardless to whom they report. They turn to various senior staff in their districts for consultation depending on particular issues and concerns. They also work closely with various medical and oncology staff to ensure appropriate care. The channels of reporting do not limit the role and working relationships. The role should be integrated with acute care, medical care and continuing care.

It is evident that there are multiple demands on Navigators' time. Workload and time management is important and there appears to be room for efficiencies. The Navigators in each district indicated the amount of paperwork required in their role is a frustrating aspect of their job, as there is a lot of duplication. Their suggestion is to reduce duplication or to have appropriate clerical assistance.

Database

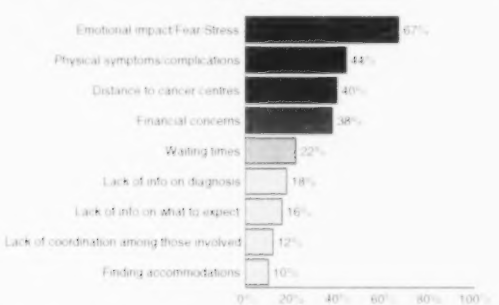
A database was developed for the program to track information on referrals and actions taken to resolve issues. This database provides an important source of continuous information that can be used for quality improvement for the program over time. The lessons learned from the early stages of the database design and use should be used to develop a more robust system.

Conclusion 3

Cancer Patient Navigators have had a positive impact on patients/families, health professionals and has resulted in improved community cancer care.

Survey and focus group results confirm that patients are experiencing a multitude of challenges following a cancer diagnosis. The emotional impact and fear of the diagnosis are the primary concerns. Other issues and concerns identified through the patient telephone survey and focus groups include physical symptoms/complications, travel to cancer centres, and financial concerns, among others. Figure 4 captures the issues and concerns of patients, as outlined in the patient survey.

Figure 4. Issues and Concerns During Cancer Experience



Source: Patient Survey

Health professionals identified a number of improvements that have occurred with the implementation of patient navigation. These include: (a) better patient preparedness, (b) more patient support, (c) improved

communication and collaboration among professionals, (d) more efficient physician involvement with patients, and (e) identification of service gaps.

A number of family physicians and oncologists reported that the patient navigation program has **helped them focus on cancer patients' medical issues**. They explained that they are not necessarily more or less involved with a patient, but rather the focus of their involvement has changed. They can focus more on the medical aspects of cancer patients' diagnosis and spend less time discussing logistics such as how to book appointments or where to go for tests. These physicians indicated Navigators help patients deal with the psychological aspects of having cancer, as well as assists them with such things as booking appointments, finding transportation and accommodations, and finding financial aid where necessary. This allows physicians to focus specifically on their medical area of expertise and was seen as being significantly more cost and time effective.

> *"It hasn't changed the level of involvement. What it has changed is the nature of the involvement of a given visit. So the involvement may be more focused on treatment related issues or relapse specific issues or disease specific issues, as opposed to practical issues. I can sit there and talk to them about how to arrange a drive to their appointment, but that is a very, very expensive use of my time." Specialist*

> *"It certainly has eased the amount of time that I have to spend with a patient on non-clinical issues and my secretarial time with patients having to describe where to go, when to go, procedures for follow-up with the specialists. It's been a boom in terms of time efficiency." Family Physician*

The Navigators are the central linkage when dealing with concerns outside of the cancer diagnosis and treatment. Patient Navigators, with their extensive knowledge of the cancer care system, can better coordinate care for patients, eliminating unnecessary trips to the province's cancer centres. This has decreased the burden patients face in arranging transportation and accommodations when they must travel to receive treatment.

The financial impact of a cancer diagnosis is identified as an issue needing patient navigation assistance. Patient and family focus groups, patient surveys, and interviews conducted with health professionals and community partners identified that Patient Navigators have been effective in helping many patients and their families access available funding sources and lobbying on behalf of patients. They are credited with discovering methods of accessing financial assistance that were previously not known to health professionals and the general public. The patient survey, found that 67 percent of patients were satisfied with the level of assistance the Navigator provided with financial issues. According to the database, Navigators were unable to resolve financial issues 25 percent of the time.

The findings of this evaluation indicate that patient navigation has also helped increase access to supportive, rehabilitative, and palliative care services for cancer patients and families in their own community. The Patient Navigators referred 62 patients to palliative care, largely in Pictou County Health and in GASHA where formal palliative care programs are established. South West Health did not have a formal Palliative Care Program during the evaluation period.

Findings indicate Patient Navigators are effective at coordinating the logistics of accessing the cancer system. Results indicate physicians, in particular family physicians and oncologists, do not have the time to do so nor are they fully aware of all the resources which can assist patients.

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Conclusion 4

The program has been successful at bringing notable benefits to the development and utilization of cancer care in the "early adopter" districts.

The evaluation considered the impact patient navigation has had on the development, organization, and utilization of cancer services. Those who participated in the community partner focus groups, along with district personnel, and health professionals indicated the program has been successful at bringing notable benefits to overall cancer care in their districts, including more awareness and utilization of community supports, identification of service gaps, increased collaboration among health care members, improved coordination of community services, and a new source of oncology expertise to the community. In addition to the introduction of the patient navigation program, many felt that establishment of district cancer care committees and *CCNS*' direct involvement within both of these programs has served to give cancer care a higher priority at the district level.

A spin-off benefit of patient navigation, highlighted by a number of health professionals and leaders, was the identification of service gaps that exist at the district level. Service gaps frequently cited by participants included the financial burden, from the cost of prescription drugs and medical supplies to the cost associated with travel and accommodations and lack of support groups and in one district the lack of a formal palliative care program. While many acknowledged that the Patient Navigators have been very resourceful in addressing these issues, it was felt that more system-wide attention is needed to address patient financial burdens and palliative care services. The districts have begun to explore identified service gaps and are working on solutions to address them.

> *"They have been able to feed back into those district cancer committees some of the gaps in their own districts and from the general discussions that we have had at different venues, you can see where these districts are taking this information and trying to move forward in improving things within their district. So I think they have been very instrumental in their districts in identifying the gaps and the things they need to improve." Community Health Professional*

Health professionals, senior leader participants as well as those who participated in the community partner focus groups acknowledged that the patient navigation program was still in the early stages. While many improvements have taken place in terms of the development and organization of cancer care services at the district, participants felt that as the program grows, more services will be established to meet the needs identified and as a result, the system will become more cohesive.

Conclusion 5

CCNS leadership, district commitment and good communication are needed for successful implementation across the province.

The evaluation has served to highlight important considerations as the patient navigation program is implemented in other health districts. There is widespread support for continuation of the patient navigation program among district staff, health professionals, community partners, and patients and families. The patient navigation program is now viewed as an integral component of cancer care services in each of the districts that were involved in early implementation.

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There are a number of key elements identified for program success. These elements include:

- Strong commitment from the district to the program including commitment from clinical, continuing care and medical services
- Recruiting a professional with the right skills and personality,
- Ongoing communication,
- Good working relationships and linkages with health professionals,
- Comprehensive orientation and ongoing educational opportunities, and
- *CCNS* leadership and expertise.

District personnel explained that support for the program has to be established among senior leaders and the board. They indicated it is important to build support from various community partners, citing that buy-in contributes to program success. A number of district personnel observed that more champions for the program, in the physician community, would facilitate greater awareness and buy-in from this key target audience.

Finding the appropriate person to fill the position was also deemed critical. Patient Navigators need to have the right knowledge and skills to be effective in the position, but they also need to have the right personality fit and level of dedication to make the program effective. They also need to be knowledgeable about community resources, about cancer and its treatment and be an effective educator. The position requires the ability to be self-managing in terms of the potential workload issues.

There needs to be linkages and working relationships with others in the district involved in cancer care. Patient Navigators must understand other health professionals' roles and make appropriate referrals. Good relationships and familiarity with the Patient Navigator will facilitate referrals.

District personnel considered the connection and support from *CCNS* as an essential component. District personnel unanimously desired a strong involvement on the part of *CCNS*. This ensures the continued coordination and management of quality of care, standards of practice, and access to provincial expertise and resources to the districts. A network of Patient Navigators, coordinated by *CCNS*, is collectively a stronger asset to the cancer system. *CCNS* can assist the Navigators with education and problem solving. Navigators rely on this support network in performing their job. Education of Patient Navigators was also considered a part of *CCNS*' role and one that the Navigators personally thought was particularly valuable.

Key challenges for the program include increasing the number and timeliness of referrals. The flexible referral process from multiple sources reduces the chances of patients being missed. More automatic referrals are also recommended to circumvent this issue. For GASHA and Southwest Health, the sheer geographical size of their district is a challenge. Strategies to ensure access across districts to patient navigation services should be considered. As the program moves forward, careful monitoring of the roles and priorities of Patient Navigators, along with their workloads, is recommended.

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Recommendations

The following recommendations are put forth based on the findings from the Cancer Patient Navigation Evaluation.

- The Cancer Patient Navigation Program should be implemented in the remaining health districts taking into account the key issues identified.
- CCNS should continue to take the lead in supporting and coordinating the patient navigation network.
- The responsibilities and priorities of the Cancer Patient Navigator must be clearly defined.
- The workload of the Cancer Patient Navigator must be continuously measured to determine appropriate balance, reduce administrative duplication, and provide appropriate clerical support where possible.
- The Cancer Patient Navigation Program should continue to address the spectrum of patient concerns and issues.
- Actions to increase the referrals rates should be undertaken.
- Consideration should be given on how to increase access to patient navigation services that ensures availability across all areas within districts.
- Ways in which patients with less frequently referred diagnoses can be reached should be considered by identifying particular sources (e.g., clinics, support groups, etc.) that could be targeted to better inform patients with different cancer types.
- The database should be redesigned to be more robust.
- Data entry by the Navigators should be considered to ensure consistent classification and data entry and to reduce the paper work.
- Communications about patient navigation with family physicians, community-based specialists and oncologists should be an ongoing process to ensure all cancer patients are aware and can benefit from the services of a Navigator.
- There is a need to work closely with community groups, organizations, and agencies to ensure that access to cancer care resources at the district and provincial level are being utilized to their maximum capacity.
- Information gathered through the patient navigation program about gaps in required services and assistance in cancer care should be compiled and shared with the appropriate authorities.

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